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Developing involvement during a programme of recovery research

Mike Slade[1*]
Premila Trivedi[2]
Ruth Chandler[3]
Mary Leamy[4]

1. University of Nottingham
2. Independent Mental Health Service User, Trainer and Advisor
3. Sussex Partnership NHS Foundation Trust
4. King's College London

*__Corresponding author__
Prof Mike Slade, Institute of Mental Health, Triumph Road, Nottingham NG7 2TU
email: m.slade@nottingham.ac.uk

Abstract

Purpose
To consider the process of working with a Lived Experience Advisory Group (LEAP) and its outcomes in REFOCUS, a large 5 year programme of recovery research.

Design
Narrative reflections on the experience of working with LEAP were collected from five members and the Chair of LEAP, two REFOCUS researchers and the Principal Investigator (PI). These were synthesised to show both the process and outcomes of LEAP involvement in REFOCUS, and how involvement evolved organically over time.

Findings
Individual reflective accounts showed how working with LEAP impacted (to a greater or lesser extent) on each individual involved in the process, providing new insights and influencing, to varying degrees, the way in which they then worked with LEAP. Synthesis of the reflections showed how these changes impacted organically on LEAP's process of involvement, with a shift in LEAP's role from being purely consultative/advisory towards one which was much more about co-production, with LEAP proactively contributing to some aspects of Refocus in the later stages of the study.

Practical implications
We stress the importance of considering process as well as outcomes in Patient and Public Involvement (PPI), and make practical recommendations for improving both in future programmes of research.

Originality/value
This is the first empirical evaluation of user and carer involvement and its development during a large recovery research programme.

Keywords
Patient and public involvement, research programme, recovery, lived experience advisory panel, process of involvement

Article classification
Case study

INTRODUCTION

Patient and public involvement (PPI) is now an expected part of UK publicly-funded health research, and overviews of supporting evidence are available (Donald, 2015). An increasing number of reports are being published as to the impact PPI can have on programmes of research (Brett, 2015, Staley, 2015). For example, a beneficial impact on ethical aspects (INVOLVE, 2012) has been identified. While these evaluations provide important information, they may not tell the whole story of PPI since they tend to focus on the outcomes of PPI but not necessarily on how and why these outcomes came about (Barber, 2008). Knowledge of these processes is vital if we are to really understand the often complex process of PPI.

In this paper we investigate these processes, using as an example our experience of PPI in REFOCUS. The REFOCUS Programme was a large 5 year programme of recovery funded from 2009 to 2014 by the National Institute for Health Research. The aim of the programme was to increase the extent to which mental health services promote recovery. The scientific content is described at researchintorecovery.com/refocus.

PPI in the REFOCUS programme consisted of active consultation and collaboration with service users and carers. Many of the ideas and concepts of recovery have emerged from those with lived experience, and the mental health system has sometimes been criticised for commandeering the recovery approach (Mental Health "Recovery" Study Working Group, 2009, Mind, 2008, Trivedi, 2010). REFOCUS therefore placed a particular focus on the involvement of those with lived experience, in an attempt to maintain the integrity of recovery and abide by the concept of 'nothing about us without us'. The journey through REFOCUS prompted considerable reflection on power relations. A prior publication considered these from the perspectives of LEAP members (Slade et al., 2010). Ironically, this resulted in some marginalisation of the perspective of the PI. In this publication, the LEAP authors invited the PI to reflect from his experience.

Service user/carer involvement in REFOCUS occurred in a variety of ways, but most notably through a Lived Experience Advisory Panel (LEAP) whose role was to review the REFOCUS programme of research and provide the research team with feedback, advice and recommendations periodically during the 5 year programme of research. At the end of the study, the LEAP service user/carers and the REFOCUS researchers provided narrative reflections of their experience of working with LEAP. Synthesis of these narratives showed how PPI was structured within the REFOCUS programme, its beneficial impact, the challenges that occurred and lessons learnt, enabling us to make recommendations for working with a LEAP in future studies (Trivedi, in submission).

For this paper we return to the original reflections from five members and the chair of LEAP, and two researchers and the Principal Investigator from REFOCUS. We use them to construct a clear, chronological account of how LEAP was set up, the process through which it worked with REFOCUS, how these processes and the role of LEAP evolved over the course of the study, and the outcomes it achieved. We present our findings as a case study, using selected quotes from the original reflective accounts to illustrate points and identify points of similarity and difference. In a nod to the unequal power relations which inevitably occur in involvement, we focus particularly on the account of the PI since he held the most power and

authority in REFOCUS and was in an ideal position to use these positively to enable PPI.

BEFORE LEAP

Right from the start, there was clear recognition by the PI and others that meaningful PPI was essential in REFOCUS, but would inevitably be challenging and demand a lot from the research team.

> *The principle of 'nothing about us without us' – partnering in research with people with lived experience — seems to me to be a core principle for ethically defensible science.* (PI)

> *Public involvement challenges researchers' values and assumptions, but in this study that was an intended goal and hence anticipated as a positive rather than a negative experience. (PI)*

> *I came to REFOCUS having previously involved the public in research within a study called Housing Decisions in Old Age. So I'm a convert, but I know how much determination and effort it takes for all involved to fully and effectively engage with non-researchers in a research study. Effective PPI needs the research team to have the capacity, energy, and determination to do it well, together with the resources of time and funds. (Researcher 1)*

Initially, PPI in REFOCUS consisted of individuals with lived experience (and at least some familiarity with research) working integrally with the research team, e.g. as members of the International Advisory Panel, as full time researchers, as advisors and consultants in specific parts of the study, as facilitators to expedite PPI in the programme of research. The decision to create a distinct group as a LEAP was made by the research team several months into the project, in response to a perceived need for more structured and collective service user/carer involvement. The idea was to structure LEAP into REFOCUS as one of 5 advisory groups who would provide feedback and advice to the research team but (like the other advisory groups), would have no decision-making power. Plans were therefore put in place to do this..

> *The PI approached me in my role as Head of Research and Evaluation at the mental health charity Rethink Mental Illness to help set up LEAP. We wanted LEAP to engage with REFOCUS in a way that could offer a critical perspective within constructive dialogue; This later became formulated as the 'critical friend' approach. (LEAP Chair)*

Initially, the plan to set up a LEAP seemed quite straightforward.

> *We had a discussion about how to recruit members to the LEAP, and decided to approach people with personal experience who had also a keen interest in or prior experience of research involvement. (Leap Chair)*

Recommendations at this stage

1. Start early! Plan PPI in advance across the full research cycle so it can be used

when developing the research idea and design.
2. Plan to incorporate PPI in a variety of ways, bringing in service user consultants and facilitators with particular knowledge/skills at appropriate points
3. Firmly embed PPI into the structural framework of the project,
4. Ensure PPI is adequately resourced in terms of time, energy and money – it always takes more than you might anticipate
5. Approach Research Design Service to see if they have any funds to support PPI design consultation

RECRUITING TO LEAP

Recruiting to Leap proved more challenging than expected. When approached to join LEAP, several service users expressed serious concerns with the way REFOCUS was operating, e.g. the late introduction of LEAP into the study.

> *I feel moved to express my amazement at the absence of service user involvement in the development and design of a study about an issue that is so fundamentally about a personal experience and a personal and individual journey. Whilst I do acknowledge efforts at getting service user/researchers involved, it is too late in the day. [Prospective LEAP member who declined to be involved]*

Others had issues with aspects of the scientific design, in particular the methodology it was using.

> *The REFOCUS programme chose to use a research design building on a positivist tradition that utilises RCTs and the development of quantitative data. This felt very alien to the nature of recovery, which seems to require a focus on the experience of the journey and the very individual nature of recovery. (LEAP 3)*

Some also expressed concerns about the inclusion/exclusion criteria being used in REFOCUS (Trivedi, 2010).

> *On reading through the full project proposal I came across the statement that 'To reduce complexity, some important aspects, including BME and carer perspectives, will not be addressed'. Given the over-representation of young Black men in MH services, having a major project like REFOCUS explicitly state that it will **not** address BME perspectives made it very difficult for me, as a BME service user, to consider being involved in the study. (LEAP 5)*

> *If BME issues are not going to be addressed, how is it going to be meaningful to assess cross cultural validity of the study? (LEAP 2)*

While expecting and wanting a critical perspective, the PI and Chair of LEAP found responding to these often vehemently expressed concerns challenging at times.

> *Recovery-oriented research requires the capacity to hold difference between perspectives as part of its process, The absence of a guiding theoretical framework for synthesising multiple perspectives may have*

> *contributed to the burden for the research team in responding to service user/carer concerns.* (PI)

In spite of this, the PI made a clear attempt to personally acknowledge service user concerns as they arose, provide explanations of why REFOCUS had taken certain decisions and pro-actively discuss and address the concern where possible within the constraints of REFOCUS.

> *Incorporating lived experience often means that service users may have a strong emotional and ethical investment in the research, rather than one solely based on positivist scientific principles of methodological soundness. Some may feel that this latter approach to recovery – framing deeply personal experiences in quantitative terms – alienated them from the recovery approach and the user values to which they aspire. However, these considerations had to be balanced against the scientific requirements of the study and remain pragmatic about what can be measured. (PI)*

Service users reacted to the PI's responses to their concerns in a variety of ways, e.g. with regard to concerns re methodology.

> *I agreed with objections to the positivist methodology planned but I could also see that, while REFOCUS 'speaks the speak' of dominant research paradigms, it probably has had to do so e.g. in order to secure funding and acceptance from the scientific community. Sadly, it is this kind of 'speak' that leads to changes in NHS practice and it may therefore have to be used in order to bring about the change we want. You have to be in it to change it, but this also begs the question of how far 'it' will change you! (*LEAP 2)

> *Although the research team had some sympathy towards our viewpoint, they chose to focus on the positivist tradition of research as they felt it generated data that was more valid and the research would be more respected and meaningful. There was much discussion and researchers listened at the start, but then focused very much on the approach they wished to take. (LEAP 3)*

While LEAP's concerns re methodology could not effect change, concerns about the exclusion of BME perspectives had a more positive outcome.

> *LEAP made the case for culture and ethnicity to be a focus of the research, and this was implemented through extending the study in a number of ways, improving its design and creating a closer match with the community's needs and interests., (PI)*

> *When I heard that issues re culture and had been raised at a higher level and that a PhD student was appointed to specifically focus on BME perspectives in the study, I decided to cautiously join LEAP since it did seem as if, in some instances, we might be able to really influence the programme of research . (Leap 5)*

Even where concerns could not be directly addressed, in some cases raising awareness of the issues resulted in indirect positive outcomes.

> *REFOCUS was not able to address the gap on recovery for caregivers within budget. However, this gap inspired a book on recovery for caregivers (Chandler, 2013a) as a platform for further research.(LEAP 2)*

Finally, after many discussions and a rather stormy period of recruitment, 5 service users and 1 carer, all with lived experience and varying degrees of research experience came together for a range of reasons to form LEAP.

> *My acquaintance with Professor Mike Slade [PI] began through my involvement with University College London's group of academics. Through this acquaintance I was delighted to join LEAP some time later. (Leap 1)*

> *I brought a critical academic perspective rooted in philosophy of history, temporality and post structural and post feminist theories and critiques of epistemology and ontology My decision to get involved was based on the word 'critical' in the terms of reference for LEAP. (LEAP2)*

> *I came into LEAP as a service user, PhD student, researcher, with responsibility for the development of service user and carer involvement in social work training at Anglia Ruskin University. (Leap 3)*

> *I learnt of this piece of research through FACTOR (Families And Carers Together On Research) and I wanted to discover if REFOCUS would offer any improvement in services through a more holistic approach. As a carer I felt I had lots of personal experience of services and the way the illness effects a person, their relatives and others.(Leap 4)*

> *I was torn at the start between working constructively together with LEAP to achieve change or staying on the outside to demonstrate opposition to the issues in Refocus I felt strongly about. (Leap 5)*

Recommendations at this stage

1. Before recruiting, hold an introductory session for potential public contributors to get a feel for the project and some of those involved.
2. Make very clear from the start the purpose of PPI and what is required of public contributors, but be prepared to modify this according to the concerns/challenges those with lived experience bring to the project.
3. When recruiting public contributors, aim to get a broad selection of members so that the study can benefit from diverse life and MH experiences, views etc.
4. Aim to recruit at least 10-12 people so there are likely to be sufficient numbers at each meeting to ensure useful and full discussion
5. Put in place a proper recruitment and selection process to convey the 'professionalism' of PPI and the commitment that is required on all sides
6. Once recruited, provide members with some form of induction in order to develop

a ‘team spirit’ and offer training as needed
7. Enable those with specific knowledge who do not wish to join a LEAP group etc. contribute to the study in other ways

STRUCTURING LEAP MEETINGS

Careful consideration was given by the research team as to how LEAP meetings would be structured. It was planned that all LEAP meetings would be held at Rethink (a mental health charity involved in the study), to provide a less power loaded space for discussion than the study team base at the Institute of Psychiatry. Each meeting would last 5 hours and work to a fairly formal format, but be arranged around a one hour lunch break in order to offer a relaxed social space and networking opportunity within the formal structure of the meeting. It was anticipated that the PI and one or two REFOCUS researchers would attend each LEAP meeting in order to enable the efficient two way transfer of information, comments, concerns and recommendations. Importantly, LEAP members would be paid £150 per meeting plus travel.

Although thoughtfully planned, the format of the Leap meetings did raise some concerns once they began, with some interesting similarities and differences in individual perspective.

> *Some LEAP members requested better introduction to the group, in order to get to know members better, feel more ‘safe’ with recognition of the challenge of evoking personal experiences during formal interactions. (Chair)*
>
> *I felt I didn't really get to know other members of the group and I wonder if it would have been useful to have had an induction to LEAP, or done some team building work before formally beginning work as LEAP. (Leap 5)*
>
> *The meeting structure was relatively formal, but generally it was felt to be appropriate given the nature of discussions and LEAP members’ experience and expertise both in respect to lived experience of metal health and research issues. (Chair)*
>
> *The style of meetings was formal and focused on ‘paperwork’ – more creative and interactive approach could have been used. (Leap 5)*
>
> *From the first meeting, I found the structure and language used in the project very complex, and it took me a few meetings to unravel what was going on. (Leap 4)*
>
> *Occasionally I felt that I had to probe and question REFOCUS' views. This was always considered in a positive way, which reflected the view that objections are merely a request for further information. (Leap 1)*
>
> *Initially we thought that the REFOCUS researchers could attend only part of the meeting in order to provide an update and answer questions, but it was decided by the LEAP members that it was helpful to have the researchers present throughout. This I think was in recognition that the*

> *researchers were always keen to listen to LEAP members' concerns and engaged constructively with these. [Chair]*
>
> *I sometimes found it off-putting having the researchers there for the whole meeting. They were very nice and respectful but I just felt constrained sometimes and longed to be able to more be me as I usually am with other service users. I also felt we tended to address the researchers rather than each other in our discussions. Having some time on our own may have helped build more 'team spirit'. [LEAP5]*

Some LEAP members felt that the diversity within LEAP was not always acknowledged, valued and used to best advantage.

Recommendations at this stage

1. Ensure meetings are scheduled in a way that ensures continuity and consistency; and (sensitively) makes clear to members that their attendance is expected and important both for the group and the wider project.
2. Ensure meetings are effective and engaging; consider using more interactive style of engagement as well as formal discussion of paperwork format.
3. Facilitate meetings to enable group cohesion and provide opportunities / activities for differences (and similarities) to be acknowledged, shared, valued and used productively.
4. Consider having some time just as the PPI group in order to foster positive team dynamics within the group.

THE ROLE OF LEAP

Terms of reference for LEAP and its precise role in REFOCUS were established at the first LEAP meeting amidst some controversy. In keeping with PPI on most NIHR funded studies, LEAP's role was purely advisory with no formal decision making power.

> *The issue of control over the research has been noted by others as a negative, although we found that careful drafting of terms of reference and the existence of positive pre-existing relationships greatly reduced this issue (PI).*
>
> *We wanted to have a critical dialogue with those with lived experience and experts in research, so developing a critical friendship model of involvement was important. It was both challenging and rewarding, and helpful in lots of ways, not least identifying biases and assumptions in the research team. [PI]*
>
> *My decision to get involved was based on the word 'critical' in the terms of reference for LEAP. On reflection, it has been a credit to the study team that they have been open to the critical friendship approach which embeds recovery orientated practice into the way we do research. [LEAP2]*

Some LEAP members expressed concerns as to how critical they could be and still work usefully within the REFOCUS structure, while others felt that LEAP's role

appeared to be rather tokenistic.

> *User involvement was very much on the terms of the REFOCUS programme. For user involvement to be valid, authentic and meaningful, it needs to respond to the views of service users and carers, not just be tokenistic or consultative. [LEAP3]*

In order to avoid tokenism and develop a mutual learning encounter, LEAP asked the PI to record recommendations made by LEAP, how they were responded to and the reasons for each response. This was implemented for the first 7 months of the study and then published (Slade et al., 2010), but then had to be discontinued.

> *The 'Recommendations Grid' showed that our comments were valued and had or had not been acted upon and in some cases the reason why. [LEAP4]*
>
> *I felt use of the recommendations grid was innovative and worthwhile but In my opinion, if we had continued this exercise throughout the study, other things in the programme would have suffered. [Res1]*
>
> *We undertook a PPI impact assessment study in order to develop and implement a methodology for differentiating between token and genuine PPI input. Overall, in REFOCUS PPI, 103 (60%) of the 172 recommendations were implemented, and we found no evidence of lower implementation of recommendations made by LEAP. [PI]*
>
> *An aspect I found challenging in terms of responding to recommendations was being the budget-holder for the PPI component. When the employed research team had a good idea which could be incorporated into their work then no financial pressures were created, whereas when LEAP members had a good idea for an un-planned (and therefore un-budgeted) contribution there were financial implications which I had to balance – leading perhaps to the impression of more hesitancy on my part in taking up ideas from LEAP than from the employed research team. An alternative arrangement would be to devolve responsibility for the PPI budget to the LEAP Chair. Also, human resources are needed to process advice, and LEAP certainly had lots of suggestions! I had to balance this helpfulness with the capacity of the employed researchers, so when the team were fully engaged in data collection, LEAP meetings were scheduled less frequently. This probably reduced the link between LEAP and the study in the latter stages. One way to retain the connection would be through an alternative approach to involving LEAP in disseminating findings (PI).*

Recommendations at this stage

1. Be very clear about the role of the PPI group, and make this known across the whole research study.
2. When setting up the programme of research be very specific about the PPI tasks planned across the study so that people have clear expectations and resources are focussed on where they add most

value.

3. Be prepared for the role of PPI to adapt as the process of involvement organically adapts.
4. Consider the value of a critical friend approach in PPI.
5. Log all recommendations emanating from PPI and monitor so the impact of PPI can be clearly assessed.

EARLY DAYS OF LEAP

The first two meetings of LEAP, while interesting and thought-provoking, were also challenging and frustrating for some of those who attended

> *The first few meetings focused strongly on process, and were very critical of REFOCUS. Yes many comments were justified, but it is important to work together to overcome some of these problems. Being political needs clever thought: working from the inside and constructively. The project was as it was, and it was important to try to influence it in its current form rather than becoming hung up on what might have been. [LEAP 1]*

> *User involvement was very much on the terms of the REFOCUS programme. [LEAP3*]

As meetings progressed, ways of working constructively together were negotiated, with all parties having to show commitment to LEAP and a willingness and capacity to listen and respond to any concerns raised.

> *I found the helpfulness of LEAP input increased as my relationship with members deepened, highlighting to me that PPI needs to be integral not an add-on to a study design, and involves relationships which need nurturing. This points to the need for earlier involvement, PI commitment to the relationship and the importance of developing trust. [PI]*

With time, commitment and skilled chairing of LEAP, relationships developed and the process of involvement became less confrontational and more settled.

> *I had some concerns initially re a member of Rethink chairing the LEAP meetings, and not a service user. However, as time went on I came to value his skilled chairing and the way in which he enabled difficult issues to be brought to LEAP meetings and the development of relationships within which issues could be debated and discussed. [LEAP5]*

> *I approached my role as a chair ensuring facilitation of LEAP discussions and at times also more actively contributing to articulate perceptions and views that were coming out from discussions. Over time I felt that the PI, researchers and LEAP members were highly motivated and engaged in frank discussions and wanted to understand each other's perspectives. [Chair].*

As LEAP became more settled, the group began to fulfil its role as an advisory panel, e.g. by contributing ideas for the road shows, reviewing recruitment materials, and commenting on the service user questionnaires about their views on their treatment and their recovery progress.

> *I enjoyed very much the practical exercises which LEAP was asked to engage in. Such exercises drew on not only my experiences of recovery from psychosis but also on my practical experiences of service user involvement and sales and marketing experience. [LEAP 1]*

Recommendations at this stage

1. Appreciate there may be very different perspectives and biases and consider developing a guiding theoretical framework for synthesising multiple perspectives.
2. Take time to establish the PPI role as a critical friend to the study, acknowledging both researcher and member anxieties/concerns and enabling mutual respect to be built so that differing perspectives can be constructively voiced and discussed.
3. Be very aware of inevitable, unequal power relations in PPI and aim to use power in a positive way to enable PPI.
4. Offer some training around research terminology would help with issues of language.

MOVING FROM ADVISORY INVOLVEMENT TOWARDS CO-PRODUCTION

As relationships developed and LEAP's involvement as an advisory panel to REFOCUS grew, the expertise within the LEAP group became clearer, not only in terms of members experiential expertise about mental health but also the attitudes, skills and knowledge gained through other aspects of their lives. Researchers therefore invited them to be more directly involved in aspects of REFOCUS, e.g. in developing tools to assess recovery.

> *I had a meeting with 4 LEAP members (and email contact with one other) to help develop INSPIRE [a measure of recovery support]. This proved extremely useful and I appreciated the time and energy LEAP members gave to this. (Researcher 2)*

> *I felt that there were some meetings in which I had some 'real say'.. The INSPIRE programme enabled LEAP members to help develop the layout and questions used in the INSPIRE questionnaire intended for service users. I particularly liked the way in which INSPIRE included themes of hope, identity, connectedness, meaning and purpose, themes which are often seriously neglected. [LEAP4]*

LEAP members were also asked to directly contribute to REFOCUS by training researchers about interviewing service users.

> *We asked LEAP members to design and run a half day training course on interviewing people with psychosis for our trial research teams, which was extremely valuable and in hindsight, I wish we'd done it earlier. (Researcher 1)*

> *I found the training extremely valuable. It made me think more about how it feels to be interviewed, and to be aware of my role in this. In hindsight, I wish the training had been earlier.[Researcher 2)*

> *The training workshop helped to 'inform' researchers of the difficulties faced by people with psychosis and was an excellent way of passing on valuable lived experiences. The session received a positive response from researchers but would, I feel, have benefited from being earlier in the project. [LEAP4]*

> *Being asked to deliver the training session indicated our experiential and other expertise was being valued; also the training itself gave us a really valuable opportunity to link up with some of researchers and for me, led to a greater understanding of each others perspectives and a building of mutual respect. (LEAP5)*

Another direct contribution LEAP made to REFOCUS was in dissemination of finding, when it presented findings from the impact of PPI Case Study at the *Refocus on Recovery* conference 2012 and also at INVOLVE 2012.

> *Preparing the REFOCUS conference presentation was very useful in enabling us to review what we had been doing in LEAP, the impact we had had on the study and how the process had been for LEAP, both as a group and as individuals.[LEAP5]*

Contributing in these various ways to REFOCUS provided important opportunities to meet directly with others in REFOCUS in a collaborative, co-production environment.

> *These less formal opportunities were invaluable in developing trust, breaking down unhelpful them/us oppositions and developing shared understanding of the research endeavour while holding differences in perspective respectfully within it.*

Recommendations at this stage

1. Enable members with specific knowledge or skills to contribute in a range of ways depending on their particular experience, interests, knowledge and skills.

LATTER STAGES OF LEAP

While LEAP's contribution to REFOCUS increased in many ways as the programme proceeded, formal involvement through LEAP meetings seemed to decline.

> *At the start of the REFOCUS programme there was a high demand for service user input from the LEAP group…As they continued with the programme, there seemed less weight and less enthusiasm to consult with the LEAP group – meetings became annual rather than more frequent. At this stage, it felt very much as if the LEAP group had been marginalised from the operation of the research. [LEAP3]*

> *I feel that the ad hoc and arbitrary way that LEAP meetings seemed to be called made for lack of continuity and inconsistency: a more regular*

and structured time table of meetings could have helped. [LEAP1]

Keeping meaningful involvement of LEAP through the project was difficult. Some of the challenges were around scheduling the LEAP meetings, balancing the desire to have regular meetings with the practical requirements of needing to schedule them when they would be most beneficial for the specific research tasks. [PI]

For some, the issue of decreasing Leap meetings in the latter part of the project was compounded by inconsistency of attendance by Leap members.

Some meetings were not as well attended as hoped for, which was disadvantageous to richer and more varied input. Although this was compensated by worthwhile email communication from some LEAP members I feel this was no compensation for face to face inter-action and debate. [LEAP1]

Pity there weren't more members involved and who could attend meetings, but all LEAP members who did attend and research team members were very respectful of each other. [Researcher 1]

I feel some sadness at my own lack of involvement with the LEAP group – possibly through the changes in my own life rather than through the project. [LEAP3]

However, even with fewer meetings and low attendance, LEAP members did get heavily involved in the latter part of REFOCUS by its involvement in writing the public involvement chapter of the final REFOCUS report to funders (Trivedi, in submission). The REFOCUS team initially submitted a first draft of the PPI chapter to LEAP for editing/revision. However, in order to achieve balance in 'interpretative agency' (Chandler, 2013b) (that is the authorial power to name what is important and what is not from the perspectives of both the study team and PPI participants) a decision was made to put this chapter together in a more recovery-orientated, co-productive way. Two LEAP members substantially revised the chapter structure originally submitted by the study team to focus more explicitly on the benefits and challenges of PPI in REFOCUS, the lessons learnt and recommendations for future studies. The PI then reviewed and revised the chapter to maximise coherence with the rest of the final report.

It's only right and proper that users/carers should be involved in writing up how they have been involved in research studies and how they felt about it, but this happens too rarely. It was good that REFOCUS researchers came to us with a draft of PPI chapter, but then allowed us to revamp it to show we felt it could better reflect the process and experience of PPI in this project. [LEAP 2]

An aspect I found challenging was being the budget-holder for the PPI component of Refocus. We budgeted for LEAP members to attend advisory meetings, provide training sessions etc. but not for writing

time. In retrospect this implicitly reflected my experience with research colleagues, where writing is a core part of the job. For LEAP members, budgeting for written contributions might have provided a vehicle for greater LEAP linkage in the second half of the study. (PI)

Recommendations at this stage

1. Include a budget for PPI in dissemination.

PERSPECTIVES ON THE PROCESS

We conclude with some overarching reflections on PPI in REFOCUS.

From LEAP members:

Membership of LEAP has been overall a positive experience as it has drawn on both my theoretical views and practical experience of recovery from psychosis which I feel have been appreciated and valued… [LEAP1]

REFOCUS has been a real learning journey in which I have changed professionally and personally. It did not get everything right in the beginning but this is part and parcel of a learning journey. I am still exploring philosophical questions about the methodological positioning of this research within an epistemological and ontological paradigm shift which I would not have thought of without this encounter. Another indirect professional impact has been the development of LEAF (lived experience advisory forum) at Sussex Partnership Foundation Trust. [LEAP2]

I have learnt a great deal about the research process. It has been a pleasure to work with such dedicated professionals and I have gained such a lot from this experience. I sincerely hope that the incredible amount of work done by all in this team will be used to help many people's lives change for the better in the future. [LEAP4]

Being involved in REFOCUS has been challenging but also beneficial in many ways. It has given me the incentive and need to consider in greater depth ideas of recovery and the way in which they are being applied in mental health services. I'm still critical, but it's been very positive to feel I could (sometimes) be this way and still be heard and responded to, even within the unequal power relations inevitably inherent in REFOCUS. [LEAP5]

From the REFOCUS research team:

Whilst we have received many practical and insightful suggestions on specific research tasks from the LEAP members, the real benefits are much harder to pin down. We have been fortunate in having group of people, stayed with us through the ups and downs of the research process, and have tolerated long periods of silence from us. They have helped us develop and challenged our thinking, methods and overall approach, not been afraid to point out when they thought we were getting it wrong and insisted that we do things differently. [Res1]

This is my first experience of research, having come from a clinical background I will take these experiences, and the wider experience of trying to involve service users meaningfully with me in my future research posts. [Res2]

The input from LEAP also provided less tangible benefits, including bringing energy and a sense of the study mattering, fulfilling its role in being a critical friend by enhancing awareness of implicit beliefs, and overall making the process of the study more satisfying, even enjoyable. The contribution I found most sustaining at a personal level was the distinct intellectual space provided by LEAP, which differed from the academic settings I normally discuss studies in, and helped me to identify my implicit assumptions about what matters, how things are and how to advance knowledge [PI]

DISCUSSION

This case study has described some of the real-life processes and challenges of patient and public involvement in a large funded study. Recommendations informed by this experience have been made for all stages of involvement.

This involvement had a positive impact on the study quality. In our formal evaluation of the impact of the LEAP on REFOCUS (Slade et al., 2010), we identified the costs and benefits for study quality. Summarising the benefits, the study design was improved through a closer match with the community's needs and interests. The LEAP made the case for culture and ethnicity to be a focus of the research, and this was implemented through extending the study in a number of ways. The phrasing of questions was improved. LEAP identified that the planned approach to goal-setting should be altered to allow people to change their minds over time about their personal goals. The input from LEAP also provided less tangible benefits, including bringing energy and a sense of the study mattering, fulfilling its role in being a critical friend by enhancing awareness of implicit beliefs, and overall making the process of the study more "satisfying, even enjoyable" (Faulkner, 2006) (p. 14). A final intangible benefit for the study was to challenge the idea that traditional methodologies could be imported without problem to researching recovery. Recovery-oriented research requires the capacity to hold difference between perspectives as part of its process, in order to avoiding over-simplified and formulaic conclusions about the complex spectrum of recovery. In the study, these principles had to be balanced against the scientific requirements to remain pragmatic about what can be measured. These benefits indicate the value of public involvement through advisory committees.

We sought to follow the six values of patient and public involvement in research: respect, support, transparency, responsiveness, fairness of opportunity and accountability (INVOLVE, 2015). The particular focus which emerged was on transparency, responsiveness and accountability, and we believe we made demonstrable progress in bringing those three values into the study by valuing different assets in an atmosphere of mutual reciprocity. We made least progress in relation to fairness of opportunity. This limitation could have been addressed by giving more attention to ensuring that public involvement was open to individuals and communities without discrimination. Our LEAP comprised people who were mainly well-educated, articulate and sufficiently confident at speaking in groups to not need

targeted support. A more representative approach would have been to have advertised the roles publicly including to less represented groups, to have used a formal process of recruitment (rather than our method of approaching and inviting people to the Chair or the PI), and the inclusion in the proposal of funding for support approaches to reduce exclusion.

Other forms of involvement, for example through peer review (Staley, 2016) and in trials (Gamble, 2015) are also being evaluated Overall, the impact of patient and public involvement in research is positive and increasing.

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